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## Sex, gender identity and (older) age

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# **Sex, gender identity and (older) age: Impacts on healthcare disparities for women with autism in the Netherlands**

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## COLOFON



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**Terminology:** The term *autism* is used in this report, rather than autism spectrum disorders, ASD or ASS, to reflect community preferences (Kenny et al, 2015), except when other terms appear in direct quotes.

# Sex, gender identity and (older) age: Impacts on healthcare disparities for women with autism in the Netherlands

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## Introduction

In recent years it has become clear that people on the autism spectrum are disproportionately affected by health and healthcare disparities (Krahn, Hammond and Turner, 2006; Emerson et al., 2011). Previous literature establishes the fact that there are disparities between males and females with autism in relation to diagnosis, and to access, duration and success of therapies. However, research is still lacking on the extent to which sex, gender and dynamics regarding the development of gender identity of individuals with autism may have a determinant impact on these disparities, and how these variables may interact with other dynamics.

A scoping review (Bishop-Fitzpatrick and Kind, 2017) found that people with autism experience barriers to access regarding autism diagnosis and care, and differential access to diagnosis and care for other conditions, including typically comorbid conditions such as epilepsy. The latter findings were strengthened by other research (e.g. Croen et al., 2015) and a scoping review focused on physical health of autistic adults (Cashin et al., 2016). Tregnago and Cheak-Zamora (2012) found that these disparities began in childhood, with higher health care utilisation and costs but, paradoxically, poorer access to care and poor service continuity.

In the UK, the Westminster Commission on Autism (2016) undertook a lengthy public review involving 900 parents, professionals and people with autism, with 74% of respondents stating that autistic people have worse or much worse healthcare than non-autistic people, and 88% specifically citing lack of understanding amongst healthcare professionals about conditions that commonly co-occur with autism. Most worryingly, researchers in Sweden have found that autistic people die on average 16 years earlier, with premature mortality a shocking 30 years earlier than non-autistic people for those with autism and intellectual disability (Hirvikoski et al., 2016). The UK autism research organisation Autistica called in 2017 for an urgent national response to this and other research indicating a high risk of early mortality for people with autism. Their report highlighted poor care for co-existing mental health conditions, and epilepsy in particular. A large US survey with a high rate of participation by autistic females found high rates of unmet healthcare needs and problems with patient-care provider communication amongst adults with autism (Nicolaidas, Raymaker and McDonald et al., 2013), including disparities in provision of gynecology and mental health services.

Prior to the present research, Dutch data on sex and gender disparities regarding health outcomes of autistic people was largely missing.

This study aimed to understand the experiences of natal female adults with autism in the Netherlands in relation to diagnosis, access to treatment, and healthcare through a mixed-methods approach that included a scoping study using data from the Netherlands Autism Registry (NAR), and further exploration via interviews and focus group discussions.

This data was used to map pathways to care for females with autism, and to identify possible barriers and enablers that are frequently encountered by or specific to women. This mixed-methods-based process of shared analysis made it possible to not only highlight the difficulties experienced by autistic women in their encounters with the Dutch healthcare system, but also to suggest methods to address these, including communication methods that better meet the needs of women with autism and have the potential to address inequalities.

The primary research question was:

*How do natal sex and gender identity impact diagnosis, treatment and health outcomes for natal female individuals with autism across the lifespan in the Netherlands?*

## Methodology

The research implemented a mixed-methods design of a sequential explanatory nature. First, quantitative data was analyzed. The aim of the quantitative data analysis was to identify patterns in healthcare access and utilization for different natal sexes and genders, including any differential impact of (older) age. This analysis was then used to guide qualitative data collection, which focused on in-depth exploration of the barriers and facilitators faced by females with autism in relation to diagnosis, access to treatment and healthcare across the lifespan.

### Quantitative research

The Netherlands Autism Register (NAR) is a longitudinal register including individual records related to approximately 2500 individuals with autism. The NAR was established by the Dutch Association for Autism (Nederlandse Vereniging voor Autisme, NVA) in collaboration with the Vrije Universiteit Amsterdam (VU). Baseline and follow-up data are collected annually using a variety of measurement tools.

The NAR collects data on age and natal sex for all participants, and began to differentiate between sex and gender/gender identity in 2016. This data has already evidenced that people with autism are somewhat more likely to question gender norms and heteronormativity than non-autistic people (de Winter, de Graaf and Begeer, 2017).

It does not yet collect specific data about health outcomes, but useful data for our purposes could be derived, including information about autism diagnosis, comorbid diagnoses, medication and alternative medicine use, and overall wellbeing.

### Sample description

At the time of the analysis, the data for 1156 adults was collected in NAR. These individuals filled in the NAR survey in 2017 or 2018. There was a large variability of age. Mean age of the participants was 43.6, with SD=13.78. The minimum age was 17 and maximum age was 86. Age group distribution can be seen in *Table 1*.

	Frequency	Percent
<19	8	0,7
19-30	242	20,9
31-40	234	20,2
41-50	284	24,6
51-60	242	20,9
>60	146	12,6
Total	1156	100,0

**Table 1: Age distribution in NAR sample**

Gender data was collected via two variables: gender at birth and felt gender. Gender at birth was presented as a binary variable (female/male), while felt gender had other options, namely: partially female and male, neither male nor female, do not know (yet), other. The sample analyzed for this research was 55.4% female at birth. Felt gender distribution can be seen in *Table 2*.

Gender	%
Male	41.6
Female	45.1
Partially male/female	6.5
Neither	4.2
Do not know (yet)	1.6
Other	1

**Table 2: Sex/gender distribution in NAR sample**

The majority of the participants were heterosexual (66%), 6.4% were homosexual and 19.5% were bisexual, while 8.2% chose the category “other” regarding their sexual orientation.

The sample analysed was not particularly ethnically diverse, with 91.7% identifying as ethnically Dutch (see Table 3).

Ethnicity	%
Dutch	91.7
Surinamese	0.5
Antilles and Aruba	0.4
Indonesia	0.9
Other Western	4.5
Other non-Western	1.8
Not clear	0.7

**Table 3: Ethnic background distribution in NAR sample.**

### *Focus of analysis*

The NAR database is focused on experiences related to autism rather than general health, but it was possible to examine data on a variety of health- and healthcare-related factors. The hypotheses of the analysis were focused on the difference between populations defined by gender at birth and/or felt gender regarding various health and healthcare-related variables:

- age of first concern about autism
- age at diagnosis
- who suspected need for diagnosis
- therapeutic interventions recommended after diagnosis
- presence of previous differential diagnosis before autism
- presence of additional physical and mental health conditions
- satisfaction with autism-specific healthcare
- satisfaction with various medications
- use of alternative medicine
- general well-being

Due to the nature of the variables (gender was presented as a categorical variable), the tests used were univariate analysis of variance (ANOVA) and Chi square. Results were considered significant with  $p < 0.05$ . Data was analysed using SPSS (IBM Inc.). Results derived were used primarily to determine topics for further qualitative research, and as descriptive data for use as a check against qualitative data.

## Qualitative research

Qualitative data was collected via both individual interviews and focus group discussions, as for some individuals participation in a focus group discussion could be too difficult or overwhelming. Individual interviews could be in person, by telephone or Skype, or via e-mail or WhatsApp.

### Recruitment of participants

Recruitment of participants was executed via collaboration with Monique Post of Vanuit Autisme Bekenen (VAB). Ms. Post played a dual role in the research project: as an expert by experience who advised the VU researchers about key issues and ensuring accessibility, and as an invaluable part of the research team, including recruitment and focus group facilitation.

A recruitment email, which included general information about the research as well as possibilities for participation and a link to a Qualtrics form for participants was sent to the network of VAB, which included a large number of individuals but also other autism organisations. It was also shared via Facebook, LinkedIn and Twitter, and passed on via the Female Autism Network of the Netherlands (FANN), a specialist practitioners' network. Potential respondents were requested to share their contact details as well as preferences regarding communication and participation methods, including whether they preferred to be interviewed in Dutch or English. Over 100 autistic women contacted the research team; of these 39 (14 interview participants + 25 FG participants) decided to participate in interviews or focus groups at this time. All research participants had received a formal autism diagnosis.

### Interviews

Interviews aimed to discuss with each participant their path to autism diagnosis as well as their life-time experiences with healthcare provision and healthcare providers. The discussion of healthcare was all-encompassing, not limited to autism. The interview guide had a life-story structure and consisted broadly of four themes:

- Demographic information
- Path to autism diagnosis
- Personal experiences with healthcare providers and services, including both mental and physical healthcare
- Advice regarding improvement points for healthcare organization and provision

Eight semi-structured interviews were conducted via email, one via WhatsApp, and five via telephone or Skype, and for a total of 14 interviews. All participants who agreed to be interviewed were natal females who identified as female. Informed consent was obtained prior to all interviews. All audio interviews were recorded and transcribed verbatim. The age range for interview participants was 28-70, with a median age of 39.5.

### Focus groups

Focus groups had similar goals to the interviews, but built more on the potential for interactive methodology. Rather than collecting individual stories and experiences of each participant in detail, the focus group structure was designed to elicit common experiences and patterns, and especially to generate possible solutions to the barriers and difficulties experienced. Participants were asked to place everyday and specialist healthcare experiences into two columns (positive or negative); some participants placed experiences on the line between the two. Advice for clinicians and ideas about ideal care were also elicited during this process.



Five focus groups were held: one in Rotterdam, two in Utrecht and two in Amsterdam. The total number of focus group participants was 25, with group size ranging from 2 to 7 (average = 5). The age range for focus group participants was 21 to 57, with a median age of 41.

All focus groups had two facilitators, and attention was given to the sensory profile of locations (lighting, noise, etc.) and ease of access via public transport. Participants were provided with information in advance about the topics, what to expect, and practicalities such as public transport details, maps and photos of the building. Informed consent was obtained at the start of all focus groups. Focus groups were held in both Dutch and English, depending on participant preference.

Both interview and focus group participants reflected geographical and SES diversity. Most participants were ethnically Dutch, except for one from a Dutch-Asian background, one from a Dutch-Middle Eastern background, and one from a non-Dutch European background. See *Appendix A* for additional demographic details.

### Note regarding gender and gender identity

The aim of the project was to look at sex and gender disparities, considering health and healthcare disparities related to both sex at birth and felt gender. It was theoretically possible to do so for the quantitative analysis, as such distinction was made in the NAR database. However, during the process of analysis we discovered that the frequency of cases of birth gender differing from felt gender were very rare, as were cases of non-binary felt gender expression (154 out of 1156). This sample was not large enough to make any definite claims regarding disparities related to felt gender/birth gender differences.

During qualitative data collection we were unable to identify and recruit participants whose felt gender differing from birth gender. Therefore, no information could be derived from qualitative research regarding effects of felt gender/birth gender disparities on health outcomes.

### Ethical considerations

The research has been conducted following the Dutch Code of Scientific Conduct. Written informed consent was obtained in advance from all focus group participants. Written and/or verbal consent was obtained from all interview participants. Before asking participants to sign the consent form, we informed them about the research objective, the kinds of questions they would be asked, how their data would be used, and their right to skip questions or withdraw from the study at any time. The information was explained in lay terms and in an accessible format for autistic people, e.g. verbally and in writing, leaving room for participants to ask questions and ask for clarification. We relied on the concept of presumed competence (Biklen and Burke, 2006) rather than setting IQ-based or other guidelines. All participants were able to communicate verbally and/or in writing.

The quantitative dataset was completely anonymized by the NAR database managers before it was provided to our team. A Data Sharing Agreement was agreed and signed by all parties.

Qualitative data in the form of interviews and focus groups was transcribed verbatim and anonymized before analysis. However, complete anonymization was challenging due to the amount of personal detail provided. All data was therefore stored at all times on a secure, password-protected server.

## Results

During our analysis several major themes that influenced the health status and the health care utilisation of autistic women were identified. First, we investigated the current mental and physical health status of autistic women in the Netherlands; we then looked into possible explanations for our findings.

One of the major themes was that receiving an autism diagnosis, including the path to it, difficulties and delays, reactions to it and consequent perceived shifts in societal expectations afterwards had a long-lasting impact on the women's mental and physical health. Stress, anxiety and trauma appeared to contribute to (psycho)somatic complaints, pervasive problems with sleep regulation, fatigue and burn-out.

Another important factor influencing the current health status of autistic women was found to be the lasting impact of previous experiences with the healthcare system (both physical and mental).

The final topic of our investigation was an inventory of current tensions and practices within the healthcare delivery system that cause diminished healthcare service utilisation by autistic women, and the solutions mentioned by our participants that can address these.

### Current health status

Within the topic of current health status, we explored both physical and mental health complaints of the participants, as well as their general self-assessment regarding their vitality, daily life and well-being.

### Mental health

When talking about mental health issues, females in our quantitative sample were more likely to have one or more current co-morbid psychiatric diagnoses:  $\chi^2(2,1096) = 16,524, p = .000$ ; and to currently use psychiatric medications:  $\chi^2(2,1096) = 12,751, p = .002$ . When analyzing the co-morbid disorder pattern, we saw a similar tendency as with the issue of previous diagnoses: increased prevalence of anxiety, depression, eating disorders and trauma (see *Table 4*). The noteworthy difference is that after the official autism diagnosis, there was no significant difference in the prevalence of new personality disorder diagnoses, such as borderline personality disorder (BPD). This may be due to the fact that autism in females can be commonly mistaken for BPD (Dudas et al., 2017).

	Female cases	Male cases	$\chi^2$
Depression	142	77	$\chi^2(1,1156) = 9,644, p = .002$
Anxiety, phobia and OCD	74	32	$\chi^2(1,1156) = 9,744, p = .002$
Eating disorders	31	3	$\chi^2(1,1156) = 18,100, p = .000$
PTSD/Trauma	52	15	$\chi^2(1,1156) = 14,141, p = .000$

**Table 4: Comorbid mental health diagnoses after autism diagnosis, female vs. male**

The picture for those whose felt gender was both male and female, or undefined, was similar to that of natal females as regards self-reported comorbid psychiatric diagnoses, type of diagnoses and medication use. Women were significantly more likely to use medication for autism-related symptoms, such as anxiety, compared to men:  $\chi^2(1,1096) = 14,427, p = .001$ .

## Physical health

Regarding the state of physical health, several aspects were investigated in both the quantitative and qualitative sample. In the quantitative sample, initial analysis was performed on questions dealing with presence of current health complaints.

After running a Chi-Square analysis, it was discovered that there is a significant correlation between gender (both natal and felt) and presence of physical complaints. Women, people who feel partially female, and those who identify as neither male nor female were more likely to have current physical complaints. For female gender at birth:  $\chi^2(2,1156) = 41,866$ ,  $p = .000$ ; for felt gender:  $\chi^2(10, 688) = 39,896$ ,  $p = .000$ . Significantly more women reported having allergies ( $\chi^2(1,1156) = 38,988$ ,  $p = .000$ ), stomach and bowel disorders ( $\chi^2(1,1156) = 19,489$ ,  $p = .000$ ), headaches and migraines ( $\chi^2(1,1156) = 28,113$ ,  $p = .000$ ) and fatigue or sleep problems ( $\chi^2(1,1156) = 26,056$ ,  $p = .000$ ). However, women were not more likely than men to be diagnosed with sleep disorders, indicating a possible barrier to diagnosis.

Older age also was a significant predictor of physical complaints (see *Table 5*). For this a binary logistic regression was run, which showed that increasing age was a significant predictor of increased probability of the presence of physical complaints.

		S.E.	Sig.	Exp(B)	95% C.I. for EXP(B)	
	B				Lower	Upper
Age	-0,025	0,002	0,000	0,975	0,971	0,980
Constant	0,466	0,083	0,000	1,594		

**Table 5: Probability of presence of physical complaints**

However, binary logistic regression looking at the possible combined effects of age and gender at birth on the likelihood of physical complaints showed that despite the fact that both older age and gender were significant predictors of the outcome variable “presence of physical symptoms,” the effect size of gender was much larger than that of age (see *Table 6*).

	B	S.E.	Wald	Sig.	Exp(B)	95% C.I. for EXP(B)	
						Lower	Upper
Age	-0,014	0,005	8,418	0,004	0,986	0,976	0,995
Gender at birth	0,937	0,136	47,128	0	2,552	1,953	3,335
Constant	-0,648	0,221	8,603	0,003	0,523		

**Table 6: Age and gender as predictors of physical symptoms**

Within the qualitative sample, we asked interview participants to rate their current mental and physical health status with the participants on a scale from 0 to 10. Responses varied from 2 to 8 among the participants (mean = 5.5), with one participant unable to use the scale to describe her health. As this was a self-rating, these responses were highly subjective. However, when asked to justify their self-rating, participants opened up about the range of health complaints they were struggling with at the moment.

To give examples of the range, the participant with the lowest self-rating described her current state of health:

*“I need a taxi to get to appointments. I get tired so quickly, I have to lie down. So there’s, um, physically I have constant, chronic pain. I have, yes, you’re asking about physical things, so I don’t need to mention the depression alongside it... but there, last weekend I was so deep in the abyss, with psychosis, depression, with the feeling that I want to die, I want nothing, to not live! Crying! In bed, uh. I feel that has an impact on my body. I, my, uh...yes, I definitely believe that there’s a connection there.”—Participant, age 42*

Participants who rated their health between 4 and 6 also described chronic health problems, and many echoed the respondent quoted above that they felt their physical and mental health issues were connected. For example, one participant who gave her health a self-rating of 6 described the following:

*“Migraine. Digestive problems because of lactose intolerance. Fatigue. Sleep problems because of PTSD. Various joint problems (bursitis regularly and joint inflammation).”—Participant, age 41.*

Across the diverse responses, the trend was clear: almost all participants experienced chronic mental and physical health problems in addition to autism, but the severity and impact of these varied. These conditions may or may not have a link with autism, or with autism-related stress and anxiety. However, the way they are experienced can be affected by autism, and by responses to autism. For example, a study of young people with autism spectrum conditions in Japan found that over half had psychosomatic conditions in childhood, which were reported to “change” into mental health conditions in adulthood; girls/women were found to be more likely to have psychosomatic conditions, and receiving appropriate support in childhood appeared to have protective value (Okamoto et al., 2017). A caveat here is that having an early autism diagnosis or being female may encourage practitioners to see somatic symptoms as psychosomatic, resulting in denial of investigation or care.

Other research has found high rates of alexithymia among both children and adults with autism. Alexithymia is defined as difficulties “in identifying and describing one’s own emotions or feelings, alongside difficulties in distinguishing feelings from bodily sensations, as well as an externally oriented cognitive style of thinking” (Griffin, Lombardo and Auyeung, 2015: p. 773). This cognitive style believed to predispose people to psychosomatic disorders. In addition, both over- and under-sensitivity to physical sensations can be part of the sensory issues associated with autism, potentially leading to either over-concern with relatively minor physical health complaints or not noticing serious physical illness or injury.

Several research respondents mentioned this issue, with one saying: *“my health problems all began because I don’t notice physical symptoms the way other people do. That’s part of my autism.”* This is further discussed in the sub-section *Pain perception*.

### Well-being

Additional analysis was run in the quantitative sample. A set of questions about general well-being was analysed, as self-assessment of well-being is closely linked to both mental and physical health (CDC, 2018).

In order to investigate the general well-being of the respondents, answers to two sets of questions had been recorded in the NAR database. First, participants had been asked to rate their perceived

well-being at the moment on a 5-point Likert scale ranging from: “I feel always or almost always happy” to “I feel always or almost always unhappy.” On this item, neither gender at birth, nor felt gender were significant predictors of the outcome:  $\chi^2(5, 671) = 7,540, p = .184$  for gender at birth and  $\chi^2(25, 671) = 32,797, p = .136$  for felt gender.

However, a second set of questions asked participants to rate their level of agreement/disagreement with nine statements using a 7-point Likert scale ranging from “strongly agree” to “strongly disagree”:

1. My life goes as I wish it to.
2. My life circumstances are excellent.
3. I am content with my life.
4. I have the most important things in life.
5. If I should do it all over again, I would not change much.
6. In general I am a happy person.
7. Compared to other people of my age, I am less happy.
8. I am in general happy, I enjoy life whatever happens and make the best of it.
9. I am not generally happy. While I am not depressed, I feel I am less happy than I could be.

These questions correspond to the eudaimonic model proposed by Ryan and Deci (2001), but without the third domain of that model, relatedness. It combines two sets of questions that have been validated in other research on wellbeing, the Satisfaction With Life Scale (Denier et al., 1985) and the Subjective Happiness Scale (Lyubirmirsky and Lepper, 1999). These have previously been used with the NAR cohort to measure subjective wellbeing as it relates to special interests in autism (Grove, Hoekstra, Wierda and Begeer, 2018).

Our analysis found no significant differences for felt gender, but some significant differences were identified when taking gender at birth in consideration. When rating the statement “My life goes as I wish,” there were significant differences between males and females:  $\chi^2(7,1156) = 26,412, p = .001$ , where females were slightly more likely to give a negative response to the statement. The same trend was seen when analyzing responses to the statement “My life circumstances are excellent”:  $\chi^2(5,1156) = 23,649, p = .000$ ; the statement “I have the most important things in life”:  $\chi^2(7,1156) = 17,974, p = .012$ ; and the statement “If I should do it all over again, I would not change much”:  $\chi^2(7,1156) = 15,719, p = .028$ . A slightly less strong trend was observed regarding the statement “Compared to other people of my age, I am less happy”:  $\chi^2(7,1156) = 14,647, p = .041$ .

No specific trends in well-being were found when taking age as a continuous variable into account.

### Diagnosis and its role for health

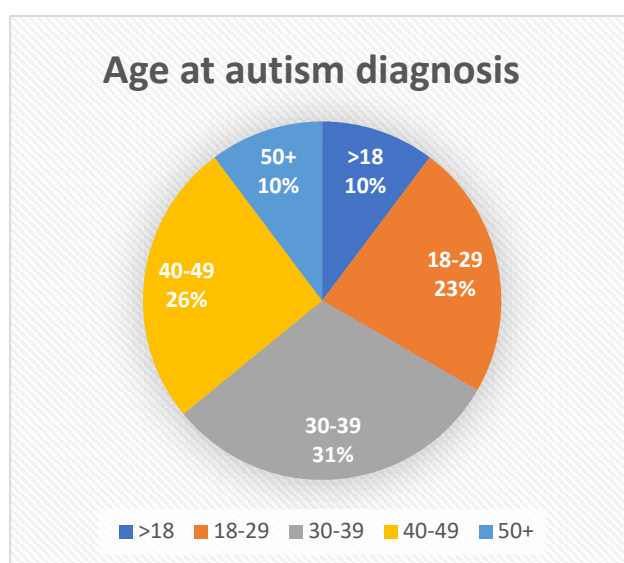
Despite the fact that the autism diagnostic pathway was not the primary target of this research, during the investigation our participants strongly reiterated that they felt many of their health complaints and issues were directly linked to their autism diagnostic trajectory, especially the difficulties and delays experienced in getting the official diagnosis.

### Early vs late diagnosis

Our quantitative sample revealed a link between gender and the age of suspected diagnosis and the age of autism diagnosis. ANOVA was conducted to examine the effect of gender at birth and age at which autism was first suspected. There was a statistically significant interaction between the effects of gender and age when autism was suspected:  $F(1, 936) = 9,132, p = .003$ . In general, autism was suspected in females later than in males. The same trend was visible when considering the effect of gender on age at diagnosis:  $F(1,980) = 21,090, p = .000$ .

Quantitative findings also indicated that there was a significant gender difference in who pursued or encouraged diagnosis. This was investigated via Chi-square:  $\chi^2(14, 1096) = 73,606, p = .000$ . Females were much more likely to self-initiate the diagnostic procedure (195 vs. 107 cases) or to be encouraged to seek a diagnosis by friends (26 vs. 15 cases), while for males the need for diagnosis was more commonly suspected by a parent, partner (75 vs. 17 cases) or schoolteacher (26 vs. 19 cases).

Our qualitative participant group included only a few women who received their autism diagnosis during their school years. For most of them, an autism diagnosis came after many years of living with no diagnosis, the wrong diagnosis (e.g. an inaccurate diagnosis of borderline personality disorder), or a partial diagnosis (e.g. an accurate diagnosis of severe anxiety but not a diagnosis of autism until later life). See *Age at diagnosis* chart, below.



Getting a diagnosis as an adult was usually experienced as difficult, as there is a limited number of clinicians available with a good understanding of how autism presents in women. Participants described waiting lists of six months, eight months or even longer for a first visit, which was only the start of what could be a trajectory lasting one or more years. One older participant said that one of her “worst” healthcare experiences had occurred during this process, over a decade previously:

*“That was with a psychologist from [practice name] in [city] who carried out the research and conducted all kinds of psychological tests for me. She seemed sure in advance that I did not have autism. Then I had to start all over again with looking for a practitioner who would take me seriously.”—Participant, age 70*

#### Path to adult diagnosis

Regarding their diagnostic trajectory, the most common theme described in the qualitative data collection was the difficulty associated with getting it. This is also reflected by the fact that the women in our quantitative sample were more likely than men to have had a different psychiatric diagnosis before receiving an autism diagnosis:  $\chi^2(2, 688) = 37,957, p = .000$ . Regarding the type of previous diagnosis, women were more likely to have diagnoses of anxiety or phobia disorders, mood disorders (i.e. depression), personality disorders (i.e. borderline personality disorder), eating disorders and/or PTSD/trauma (see *Table 7*).

	Female cases	Male cases	$\chi^2$
Anxiety	73	32	$\chi^2(1,1156) = 9,260, p = .002$
Mood disorders	118	52	$\chi^2(1,1156) = 15,728, p = .000$
Personality disorders	97	39	$\chi^2(1,1156) = 15,722, p = .000$
Eating disorders	33	5	$\chi^2(1,1156) = 15,675, p = .000$
PTSD/Trauma	30	8	$\chi^2(1,1156) = 8,782, p = .003$

**Table 7: Mental health diagnoses received before autism diagnosis, female vs. male.**

Interviews and focus groups made it possible to dive into more details regarding the diagnostic trajectory. Almost all women described difficult trajectories of being given the wrong label and the wrong medication or therapy over a period of years or decades, and feeling misunderstood by the mental health system and by those around them. One participant (age 28) explained:

*“Before I received the autism diagnosis, I had been given the following diagnoses: chronic depression (dysthemic disorder), social phobia, general anxiety disorder, panic disorder. I feel that the dysthemic disorder makes sense. Perhaps it is reinforced by my autism and I experience it more severely, but I do think that along with autism I have depression. The other disorders are strongly related to my autism.”*

A 30-year-old participant who had only received her diagnosis the previous year described her experience:

*“I have had several different diagnoses during my life. When these diagnoses were made, they were explained to me and I agreed with them. But despite treatment, problems continued to arise. I did not understand this. In the end, I thought there was a personality problem. Now that I know there is an ASD, that explains to me all the problems I had earlier in my life. I now think the earlier diagnoses were not really correct. Maybe I met the criteria for other conditions, but it can all be explained by ASD.”*

Some women experienced involuntary psychiatric treatment as a result of misdiagnosis, or due to additional diagnoses that arose at least partially because of undiagnosed autism. Inpatient treatment prior to autism diagnosis was generally experienced as ineffective, and sometimes as actively negative. However, due to a lack of autism-informed care in the mental health system, this perception of inpatient care experiences did not always change post-diagnosis.

These frustrating trajectories through incorrect or missed diagnoses were experienced as preventing participants from getting on with life, and contributed to the very common experience of “burn-out,” with ensuing disruption of education, employment and family life: at least 19 of our 39 qualitative research participants had one or more experiences of burn-out. For a number of women, cycles of increasing stress and anxiety leading to burn-out were a repetitive feature of their lives pre-diagnosis. This indicates a need for ongoing support, but as will be discussed further, the Dutch healthcare system is not geared to provide this. Women stated that in their experience the healthcare system, including the mental health system (*geestelijke gezondheidszorg*, or GGZ), focused instead on short-term “interventions,” while access to long-term support through other means, such as a personal care budget (a *persoonsgebonden budget*, or PGB, can be arranged by four different care systems, two of which are run by city governments), ran up against pervasive problems with eligibility, cost, service availability and variable quality.



### Impact of early vs. late diagnosis

We investigated this issue in our qualitative sample. Participants perceived that autism diagnosis at an earlier age had some protective value: especially younger women in this category generally received sufficient support and adaptations to complete their education, for example, and gained in self-understanding prior to encountering some major life milestones, such as completing further education, starting their career, forming a long-term partnership or having children. That's not to say that early diagnosis solved all problems: disbelief or misunderstanding by some clinicians remained a problem, and adult service provision and understanding was not reliable.

Late diagnosis was more likely to be associated with cumulative effects of stress, anxiety and depression, with all of the mental and physical health impacts that can bring.

### Response to diagnosis

The second diagnosis-related theme that influenced the health status of the women was the reaction to their receipt of an autism diagnosis by people who were close to them. It is interesting to note the duality of experiences: while most women described getting a diagnosis as a relief for themselves, most of them agreed that receiving the diagnosis, especially when it came later in life, was associated with mixed reactions from family, friends and health professionals.

For those women who received an autism diagnosis in later life, it was almost universally perceived as a great relief: The right label felt like a step in the right direction. As one noted:

*"Especially as a woman, you are always dealing so much with an environment that for your entire life tells you that you don't do this well, and 'you don't do that well, and this is wrong, and that is wrong. And if you have the autism diagnosis, then you suddenly understand: Wait a minute, I was not wrong, I was just different. You know? And yes, I sometimes hear stories about people who cannot agree with their diagnosis, but I think especially for women, the autism diagnosis can really clarify things."*—Participant, age 38

Family responses were mixed. Some women had decided to not tell family members because they expected a negative reaction; others had received negative, often disbelieving, reactions. Of course, some parents, siblings, partners or children were positive and supportive.

When asked about the reactions of health professionals to their diagnosis, participants described a wide variety of responses, both positive and negative. For example, one young respondent whose anxiety took the form of frequent health concerns was given the label of "hypochondria," but eventually found a GP who understood that needing to check and obsessionality could be part of her autism. She was told that she was welcome to make an appointment anytime she had a concern, and given appropriate attention and information when she did so. She reported experiencing reduced health anxiety as a result of this reassurance.

A 30-year-old participant noticed a significant and positive change after her diagnosis:

*"I notice that my autism support manager is tailoring things to me. A lot of understanding, a lot of quiet explanation. I also notice this with my support workers. My GP does her best to tune in to me. She responds positively to me, but is not always able to take a lot of time due to practical circumstances (busyness)."*

On the other hand, another respondent said she had a GP who knew nothing about autism: *"and because of this, he gave the wrong explanations for my complaints."* There were also several reports of health professionals, including GPs and specialists, who refused to believe the diagnosis was



accurate (e.g., “but you don’t *look* autistic.”) This was one type of negative healthcare experience that tended to reduce trust in healthcare professionals, an issue that will be further discussed later.

### Autism role vs female role

Professional disbelief, like other negative reactions, is often based on stereotypes of people with autism as children rather than adults, males rather than females, and having severe communication or behavior deficits rather than the full spectrum of possibilities that actually exist. *“A lot of people are still thinking in stereotypes when it comes to autism,”* said one participant. As she noted, encountering beliefs about autistic people that basically reflected a “Rainman” or “Kees Momma” model was a relatively common experience. Despite efforts by autistic people’s organisations and other advocates, this perception does not seem to be shifting quickly. A 21-year-old participant noted that when she was at school, the image presented of autism *“was men who often, who very often had just one interest, uh, often extremely intelligent, very withdrawn, in their own world, and that was it.”*

These stereotypes are at odds with the experiences and lives of autistic women, and call into question their ability to fulfill certain roles that are socially expected of women—roles as romantic partners and mothers—as well as their ability to work in people-oriented fields. And yet our participants were very often partners and mothers (at least 15 in our qualitative sample of 39 were parents or foster parents), and many had chosen typically “female” careers. This was not surprising, as other research has highlighted the fact that females with autism are more socially oriented than males with autism (e.g. Sedgewick et al., 2016). Girls tend to receive more explicit social skills training, and to develop strategies that allow them to “mask” their autism through performing stereotypically “female” behaviours. However, this is often experienced as effortful and stress-generating, and may further contribute to the high levels of stress and anxiety reported by our respondents (Tierney, Burns and Kilbey, 2016). There is also the issue of either the autism label or the fact that parents with autism may do things differently to contend with. As one 45-year-old, who received her autism diagnosis while hospitalised for post-partum depression and PTSD, put it: *“Some people still have prejudices: for example, that we have many limitations as parents. That we can’t raise our children properly.”*

### Experiences with healthcare

The current physical and mental health status of our participants was described by them as directly linked to their prior experiences with the healthcare system in general.

#### Negative experiences: Reduction of help-seeking behaviour

A common refrain was that their physical health complaints were, like issues related to autism, not taken seriously, even when the symptoms caused significant disruption to their ability to function day to day, care for their families, or work. In addition, delays and bureaucracy introduced confusion that led to lack of treatment efficacy. As one participant (age 32) reported:

*“Together with the doctor you go through a number of treatments before you are referred to the specialist. After a long wait, the specialist arrives, and she starts the entire treatment course again from the beginning. This was completely useless for me and I did not understand it. Protocol or not, it is totally not in my interest, or for the healthcare costs, to repeat a treatment of several months. When I got upset, the time was up (10 minutes per consultation) and I was allowed to relax/cry in a corner opposite that of the specialist.”*

Another discussed how a communication problem with the specialist diabetes nurse in her GP’s practice caused problems for management of her condition:

*“There is only one diabetes nurse, and I can’t get along with her... So I saw her four times, and three times I explained what works for me and what doesn’t. And then I said, ‘hey, I have autism, then I had just gotten my diagnosis, I have autism so with me it works a bit differently, so you need to, yes, you need to work a different way.’ And then she said, ‘oh, yes, now you have another excuse.’ And then I thought: now I am through with you! Then I had to, uh, luckily, see the diabetes nurse at the hospital, with the internist in charge, but now I don’t have to inject insulin anymore because I’ve lost a lot of weight, and now the diabetes nurse from the hospital says that I’ll have to go back to the GP. And then I said, well, I’m not going to do that. I said I won’t go back to that diabetes nurse. ‘Yes, but what then?’ Then I said, ‘well, nothing.’ Then she sent me with the results of the blood tests, and then I have to decide if it’s good or not. And I said I’ll go ask the GP to do the checks, but if he won’t, then I really won’t go back.”—Participant, age 47*

Some women reported that as a result of multiple negative experiences, they decided to not seek healthcare at all anymore unless it was an emergency. Unfortunately, this could place them at risk. For example, after we presented initial findings from our research at the annual meeting of Female Autism Network of the Netherlands (FANN), a specialist clinician’s group, two clinicians stated that they had female autistic patients who, due to lost trust in healthcare, did not approach their GPs with warning signs of cancer until it was too late.

Perhaps the most common finding here was that the systemic divide between care for mind and body created barriers to care in both domains. For example, one 41-year-old participant said:

*“The GP mainly looks for physical issues, not mental ones. And when you come to their practice time after time, and time after time say ‘I am so incredibly tired that everything takes me so much effort, my body feels so heavy... I sleep all the time,’ well, then they just take stupid blood samples again and ‘yes, we can’t find anything.’ That’s when doctors need to look further and ask themselves, ‘is what I’m doing really helping this person?’.”*

Eventually this participant was diagnosed with chronic fatigue syndrome and fibromyalgia, but it took many appointments and a great deal of difficulty.

Some participants had asked for and received support when faced with major healthcare issues, such as surgery or childbirth. When this went well, the key factor was that all members of the medical team understood the need for support and respected the woman’s wishes. When that did not happen, support fell short. As one participant said: *“When it comes to having surgery, support can unfortunately go really badly (no transfer [of information], nurses were ignorant.)”*

#### Positive experiences: Feeling supported

The experiences of healthcare practitioners were, of course, varied. Some participants could recall excellent practitioners whose understanding of autism and sensory issues helped smooth any issues during consultation. Positive practices included sharing written notes about diagnoses and treatment options, agreeing to email contact for further questions and, most importantly, listening to patients’ concerns and taking them seriously. Practitioners who gave advance notice of what they are about to do during an examination or procedure, and who explained the process and goals of therapies or treatments in some detail, were especially appreciated.

One participant (age 44) who had an emergency-room admission told us about a positive experience where a doctor noted that there was an autism indication in her file:

*"It's a different way of processing information. So yes, be clear and tell what you are going to do, so I know what kind of sensations I am going to experience. 'I am now going to do an injection,' or 'we are now going to do an MRI scan,' then I know what's coming next..."*

*The doctor asked, 'well, this is annoying, but we have to cut your clothing, is that OK?' And I said yes, if you have to, you have to. So he said, 'that's great, and now I will start cutting.' So then I knew. Then I heard a scissors and I felt it on my body, but it was OK. Then he said, 'now I need to cut your bra' and 'oh, there's something in there.' I said, 'yes, that's my money.' [and he said] 'Oh, I'll give that to your sister, then'."*

Others were able to routinely ask their GP for a double appointment, to allow enough time for communication about healthcare needs, and some women had found that bringing someone with them for communication help or just for support was helpful. Some women felt they needed extra reminders for follow-up appointments or medication refills/checks, but this was not routinely offered.

One focus group participant wrote that *"believing you and knowing about women with ASD"* were the two key criteria for a good medical practitioner. But as another woman described the more usual situation: *"In your typical GP surgery: no understanding, impatience."*

### Pain perception

The issue of pain perception and response in autism is complex, and can lead to healthcare problems. Women described living with chronic pain but not seeking care for a variety of reasons, ranging from the negative experiences discussed earlier to feeling that they were "complaining too much." Others told about how having a high pain threshold presented dangers. One focus group participant said:

*"Yes, I was sent home with a broken bone. My pain threshold is just different, sometimes something hurts very much that isn't [important], and sometimes something doesn't hurt when it should. And I had heard it break. And I have broken bones so often that I recognized the sound, that is a really annoying sound. Um, so I went to the hospital and 'hey, I think I've got something in my foot and...' 'No, that can't be, otherwise you couldn't stand on it.' [deep sigh] So I was sent home, bruising. Well, in the evening it got really weird, too blue and so on, so I went back to the hospital. Then they made photos: 'yes, yes, we'll have to call to get the orthopedist out of bed, because you have definitely got a broken foot'."*

### Alternative medicine use

In our quantitative sample, several questions dealt with the use of alternative medicine. Our analysis found that there was no gender difference except in the category of food supplements and vitamins. Females were more likely to take these:  $\chi^2(1,1096) = 14,427, p = .001$ . This is not surprising, as other research has also found that women are more likely to take supplements and vitamins than men (e.g. Skeie et al., 2009). There was no significant difference regarding use of homeopathy or special diets between men and women.

However, many participants from our qualitative sample had used some form of alternative or holistic medicine, ranging from acupuncture to Bach flower remedies. Alternative therapies that focused on the body, such as massage, were frequently experienced as effective against stress, anxiety and sensory issues. However, a sub-set of participants said they would prefer to avoid these kinds of "hands-on" therapies.

General practitioners were unlikely to be aware that their patients were using alternative medicine. Sometimes when they found out, as in the case of one participant who was using traditional Chinese medicine, their reactions were immediately negative rather than asking questions about what effects their patients actually sought or experienced. Of course, alternative therapies can have high financial costs, be useless, counteract Western medicine or be innately dangerous—but their use can be a marker that mainstream medicine is not meeting a healthcare need.

Because feeling “rushed” by mainstream practitioners and needing more time to communicate were frequent topics for participants, adequate time and attention may be among the primary needs that alternative practitioners addressed. One participant described this very eloquently: *“My experience was that this is always nicer than regular care. More time is taken and more attention paid to body/mind and the total picture of you as a person.”*

## Current tension points and possible solutions

### Tensions

#### ***Impact of healthcare environments on healthcare access***

As previous quotes illustrated, sensory issues can present challenges to receiving care and are often poorly understood—or not understood at all—by healthcare personnel. As one participant, age 39, said:

*“Due to my severe sensory issues I am almost untreatable. Simple things like taking a photo or a blood sample I can just barely handle. But if you want more than that, often it is impossible. And I have found that it is very difficult for [healthcare personnel] to understand that. Doctors seem unwilling to work on this with me or to think outside the boxes, look beyond protocols. One positive exception was the special dentistry service at [name of hospital].”*

Many participants described typical healthcare environments as presenting a sort of sensory obstacle course. “Hospitals are intimidating and anxiety-inducing,” and “Hospitals are mazes” wrote one focus group participant, while others described struggling to cope with bright lights (especially fluorescent lighting), busy patterns and colours, noise, background music and smells. One participant noted that the noise made by employees’ high heels or clogs was problematic, another mentioned that air circulation in medical offices was often poor. Add to this the likelihood that the doctor will need to touch you, possibly in an uncomfortable way in the case of injections, blood tests or physical exams, and healthcare environments can become places of dread that autistic women want to avoid.

However, as the previous quote indicated, there are some practitioners who have thought through these issues and who try to address them—not necessarily just for patients with autism, but for any patient who may experience anxiety in healthcare situations. The participant quoted above was one of several to single out dental practitioners, and this makes sense. So many children and adults experience fear and anxiety around dentistry that meeting their needs that “Special Care Dentistry” has become a recognised specialty. Likewise, some participants mentioned physiotherapists as understanding sensory issues (in particular, those with experience of working with brain-injured patients, as brain injury often gives rise to sensory issues); one mentioned a positive experience with a pain specialist, and another with a PTSD specialist.

One factor that clinicians may not be aware of is the role of anxiety leading up to an appointment. As one participant told us, *“I lay awake in a panic for three weeks, because I knew it was almost time again”* to see the dentist. Of course, this level of worry may well explode in the highly charged atmosphere of the actual appointment, especially if the environment presents sensory overload.

Specific to care received related to autism or mental health needs, there were several reports of “good” diagnostic or treatment centres being located far from the participant’s home. These distances can present access barriers, especially for women who also care for children. The overall shortage of trained practitioners in the autism field appears to be systemic in the Netherlands, and is discussed in the following section.

### ***Impact of healthcare system issues on healthcare access***

Several aspects of the current Dutch healthcare system were mentioned that impacted healthcare access. These included short appointments (most participants found it almost impossible to express themselves in the standard 10-minute time slot), being forced to see different practitioners instead of having long-term healthcare relationships, and the influence of insurance companies over the type and amount of healthcare received. As one participant put it: *“my insurance company decides how many times I can see a psychologist.”* The move many practices have made towards digital-only or telephone-only access to making appointments was also criticised. Using the telephone was experienced by many participants as difficult, and others find online systems confusing or had privacy concerns.

Specific to autism care, there is a shortage of trained, empathetic autism professionals throughout the country, but the shortage is pronounced in some geographical areas. This limits access to decent care and support. For example, one participant was only able to access a “good” autism coach by paying privately for coaching sessions with a practitioner who lived on the other side of the country. Others felt forced to put up with sub-standard help, or could not find any practitioner who met their needs. As one put it, she was faced with *“a ‘choice’ of one expert, and it was someone I had no rapport with.”*

Not only the distance but also the cost of help was mentioned. Most of the women in our qualitative sample were not working or worked part-time, and so lived on a low income. But because autism coaches are in high demand, they can seemingly name their price. One 52-year-old explained that her coach charges €80 per hour, but the city will only pay €44—the rest she has to come up with herself, which means she can’t afford help from the coach very often.

The quality and knowledge base of autism-focused professionals was described as extremely variable across the full range, from home-care workers and autism coaches to higher-level professionals. This seemed to be a particular problem for those women who had additional GGZ diagnoses, and were expected to use “generic” local mental health services. A participant who relied on one of the largest mental health services in Amsterdam provided examples of how the lack of autism-informed or autism-specialist care made her experience difficult:

*“For example, they suddenly sit down with you. Then they say: ‘well, you don’t have autism, you come across as totally normal.’ Or your arm is pulled while you say, ‘hey, ouch.’ And you have your sunglasses on and [they say] ‘now take your sunglasses off and look at me.’ And I say, ‘well, ma’am, I find that difficult.’ ‘Well, no, I’d rather you took them off.’ Those sorts of examples. Um, yes, I was there alone, and that was really painful. Yes. That’s what I can remember.”*

*I also discussed that with my psychiatrist. And he was totally shocked. That was really a [sound of shocked practitioner] ‘did they really say that?’ ‘Yes, that’s what they said to me.’ And uh, I went one more time with my support worker, the autism expert, because my trust, I didn’t trust them, I said ‘I won’t go alone.’ But I’m happy, I hope that was the last time I’m there. Because I don’t want to go there again.”—Participant, age 42.*

There were reports of improved practice in some GGZ services, however. One focus group participant wrote: *“Now finally I have someone who is working in partnership with me. We are looking together to find out what works and what doesn’t. He listens to what I need and adapts to me instead of the other way around.”*

We received many reports of poor practice from healthcare professionals, including specialists in obstetrics and gynaecology, nose/ear/throat specialists and others, as well as GPs. These were often unrelated to autism—for example, one woman overheard a practitioner (who thought she was fully anaesthetized) making comments about her genitalia, another was refused an STD test because she was past child-bearing age—but autism can cause poor or dismissive practice to have a greater impact on self-image or health-seeking behavior. There was a sense that some of the women we met had held on to past bad experiences for years, having never had a chance to discuss them with anyone, and that these had “poisoned the well” when it came to healthcare.

Indeed, even relatively minor negative experiences can have a major impact for this group of women. As another focus group participant told us:

*“The GP said: ‘I understand autism’ but then he still touches me. On my shoulder, where that isn’t needed for his profession. I don’t trust him anymore. I don’t dare to say again that it’s part of my autism. I don’t dare to stand up for myself!”*

It’s the combination of negative experiences and difficulty in communicating your opinions or needs that seems to create the greatest tension here. It left autistic women feeling disempowered, and therefore more anxious.

### ***Impact of healthcare issues on other areas of life***

Doctors are not always aware of the impact that their decisions can have on other aspects of patients’ lives. Participants who experienced involuntary treatment, for example, could see relationships with partners and children affected. Poorly managed stress and anxiety led to loss of employment and social contact for many. For one participant who had been given an autism-specific housing placement during her studies, the decision by one professional to not write her diagnosis on a form led to housing loss and being placed in unsuitable residential provision, with knock-on effects in every area of her life.

In recent years many care and support decisions have been devolved to the level of local government. The intention was to bring decision-making closer to disabled people, but the reality has been a lack of joined-up working between multiple departments, agencies, services and decision-makers. One participant (age 44) described her experience:

*“My current city has given indications [advice] over appropriate housing, over, uh, personal support, uh, over day-to-day arrangements, regarding cooperation with the UWV [benefits agency], and teamwork. And then waiting times of five to six months, and hey, that’s not even for getting the care, but just for the first appointment, to see which care you need. And then the care has to actually happen! Well, I was shocked...”*

The impact on work and education was clear. Of our qualitative sample of 39, at least 19 reported one or more episodes of burn-out, 22 women of working age were not working (of these, 4 were students), three were working part-time only, and one was employed in a sheltered workshop. This represents both a personal and societal loss.

### **Trust**

Trust came up as a tension point throughout the qualitative research. It takes time and effort to build—or rebuild—a trust-based relationship between a healthcare practitioner and an autistic woman, but current healthcare practice in the Netherlands places pressure on this practice. Short appointments offer little time to get to know the practitioner, and many women reported lack of choice, or being forced to see multiple GPs, i.e. locum doctors.

On the other hand, *being made to feel welcome* was mentioned by respondents in relation to specific doctors or healthcare facilities as a simple practice that engenders a feeling of trust.

### **Communication**

Communication is a relationship-based process, so systemic issues that do not encourage patient-practitioner relationship-building also work against communication. This can result in women needing to explain how their autism or other health conditions affect them over and over, for example. For those women who find verbal communication especially difficult, there is a clear need for extra support.

### **Environment**

The sensory and way-finding barriers presented by many healthcare environments were mentioned previously. These should be seen as disability access issues, but it was clear that many, perhaps most healthcare practitioners lack understanding of sensory issues or the need to address these in their own workplaces. These challenges do not affect only people with autism, but can be especially acute in this group.

### **Mind-body differentiation**

Because so many women experienced their physical and mental health challenges, including autism, as being intrinsically linked, the concept of the mind/body divide also seems to be a key tension point. A participant who had herself worked in the mental health system noted that it was ill-equipped to handle the physical health issues of people experiencing mental ill health. Interaction between the regular and mental health systems involved a “dramatic number of bureaucratic problems,” generally funding-related, she added: “all the ins and outs of the municipalities are very linear.”

However, several women made it clear that a holistic approach is more effective. As one participant (age 38) stated:

*“Actually, since I received my autism diagnosis, my physical complaints have reduced enormously. You know, even though I’ve put on 20 pounds because of the anti-depressants, eh, my physical health has nevertheless not deteriorated.”*

One 34-year-old participant sees a GP who specializes in care for people with developmental disabilities, and has found that he is more understanding about how she perceives her health needs. She said that typical GPs “look at everything independently, while I prefer someone who can put it together. Because all the problems are tangled up.” However, she also had a

cautionary tale about another doctor, “a ‘holistic doctor’ whose knowledge of autism was out of the Middle Ages.” Clearly it is attitude and understanding, not titles, that make the difference.

### Possible solutions

Participants offered many ideas about what an ideal healthcare situation would be for them. The following scenario combines ideas offered by all participants in the qualitative research, with the caveat that because women with autism are heterogeneous, it is always import to understand individual needs and preferences.

#### **Ideal healthcare, as described by female research participants with autism**

*Healthcare workers have a good understanding of autism, including the diversity of people with autism, and women with autism. They understand that living with autism in a world that was not designed for autistic people gives rise to a high level of stress and anxiety daily, and that this can lead to other health problems, both physical and mental. In addition, practitioners understand that many autistic women also deal with past experiences of trauma. Practitioners are knowledgeable about different forms of communication, and use these as needed. Practitioners are aware of conditions that are specifically linked to autism, such as seizure disorders, and of how a variety of common health conditions might present differently in or be described differently by people with autism—including presentation of pain.*

*As a result of these understandings, practitioners offer care that is trauma-informed, and that minimizes stress and anxiety. This is accomplished through steps ranging from sensory-friendly healthcare facilities to longer appointments, communication support (such as written information) and being made to feel welcome. Care includes screening and treatment for conditions linked to autism, stress and anxiety. Healthcare includes both mental (talk therapy, group therapy, social support) and physical (body-centred therapies, medical care) responses. Where needed, high-quality long-term support is available.*

*Providers communicate sensitively and accurately with others involved in supporting autistic women, such as specialist healthcare providers, support agencies and housing providers, upon request. Autism-informed practitioners help their colleagues to improve practice.*



## Discussion

We asked participants to describe their best and worst healthcare experiences, and the results indicate that it is possible for healthcare professionals to improve practice in ways that facilitate access to care for autistic women (and to others, including autistic men, who may share sensory issues or other characteristics with them.) An example from a 39-year-old participant exemplifies what these women hoped for in healthcare encounters, based on her positive experiences in two different specialist dental care programmes:

*“[There I found] people who were really willing to think along with me, to think outside the box. What is possible—and if something really needs to be done, how are we going to make that possible for you? I was heard and seen. And taken seriously. I can think along. In my case, for example, for anything more than a dental check-up I need sedation.”*

As this testimony indicates, it is possible to derive a list of core competencies for clinicians and other recommendations from our data. In the following two sections, these are primarily listed in the form of bullet points for brevity.

### Core competencies for clinicians

Because autism and related conditions are relatively common, all clinicians will encounter people with autism during their career—and as the diagnostic histories of our participants indicate, many of these patients will not (yet) have a medical diagnosis. For that reason, it’s important for clinicians to have the training and personal competencies required to ensure that all patients receive the healthcare they need. Based on our data, we see core competencies for clinicians as the following:

- Knowledge of autism and how it presents in adults, including women and transgender/non-binary persons
- A positive attitude about autistic people, including the ability to see them as individuals rather than in relation to a stereotypical, and typically male, image
- Strong communication skills, including an understanding of autistic communication, non-verbal communication methods and supported communication
- Excellent listening skills
- Knowledge of the stress, anxiety and trauma that often accompany living with autism, and the potential of these to impact health
- Attention to the additional physical health conditions that often accompany autism, especially seizure disorders and conditions related to living with persistent stress
- Attention to the mental health conditions that often accompany autism, including post-traumatic stress disorder, anxiety and depression
- Understanding of how autism can impact care efficacy, and skills to address this impact sensitively
- Understanding of sensory issues and how they may affect care, and skills (and willingness) to address these impacts in practices and environments

Other research has suggested involving people with disabilities in assessment of healthcare professionals (for example, Soni, Hall, Doulton and Bowie, 2014). This has promise for improving the healthcare experiences of autistic women as well. Research also supports involving disabled people in the education of healthcare professionals (for example, Simpson, 2006; Morgan and Jones, 2009; Atwal, 2018). This could help clinicians to develop the competencies listed, and to understand why they are important.

## Recommendations for healthcare service providers

In all healthcare facilities, the development of clear protocols is an important aspect of delivering care. However, these protocols are all too often developed with the “typical” patient in mind. As a result, practices may feel challenged when patients have conditions like autism, ADHD, mental health difficulties or a form of dementia, and simply don’t fit the “typical” mould. To ensure that care protocols do not create barriers to access, involving autistic people (and other disabled people) in protocol development and care quality assessments or systematic service reviews is a very helpful practice (see, for example, Barbato et al., 2014; Bray and Preston-Shoot, 2005.)

In addition to flexible care protocols that can easily accommodate different needs and preferences related to disability, key recommendations for providers that will help to address the healthcare access needs of autistic women include:

- Trust-based relationships with one professional at a time, rather than frequent practitioner changes
- Longer appointment times: many women we met with request a double appointment as standard
- Communication support tools, including encouraging autistic patients to bring or send written descriptions of symptoms, and providing written copies of advice, including step-by-step instructions when needed
- Making sure that support staff also have an understanding of autism and how it may affect people—including women who may not (yet) have a diagnosis—and are willing to adjust their practice to assist
- Attention to healthcare environments: most medical offices are now accessible for persons with physical disabilities, but bright lighting (and especially florescent lighting), highly stimulating colour and pattern schemes, unclear signage, and high noise levels can form impassible barriers for autistic patients
- Attention to healthcare communication and processes at systems level: for example, all healthcare offices should offer the ability to make an appointment in person and by telephone as well as online, and when long trajectories towards diagnosis or treatment cannot be avoided, a clear timeline and explanation should be provided.

In addition, some patients, especially women who cannot bring a parent, child or support worker to appointments to help them “translate,” may need a health advocacy service to communicate well (or at all) with healthcare professionals. Such services are not well established in the Netherlands, but are widely available in the UK (NHS, 2018) and some other countries. We did not include women with intellectual disabilities in this research, but health advocacy services will be especially important for this group.

## Limitations

The sample used for this research was limited in size, and cannot be assumed to represent all women with autism in the Netherlands. Specifically, it did not include women with intellectual disabilities or women currently living in closed institutional settings (although some participants have done so in the past). These women may have additional needs and challenges, and further research on health and healthcare disparities should be conducted with this population. The sample was not large enough to fully explore the impact of gender identity vs. natal sex, although quantitative results indicate that it is not large.

The recommendations made in this report correspond to many of those found in other recent literature on the healthcare experiences of autistic adults, including autistic women (Nicolaidis et al., 2013; Nicolaidis et al., 2015; Mason et al., 2018; Duker et al., 2019). However, implementation and evaluation of short-term and long-term impact are needed to ensure that these recommendations are sufficient to address healthcare disparities affecting this group of patients.

## Conclusion

The nature of the quantitative data available via the NAR database and our own recruited sample made a definitive comparison of the impact of gender identity, as opposed to natal sex, on access to healthcare for autistic women in the Netherlands impossible. Based on the small amount of data available, it appears that those who identify as female or non-binary encounter similar health disparities to natal females.

As regards the impact of older age, the quantitative data suggests that female gender can have a more significant impact than older age when it comes to health status of autistic people.

The qualitative data analysis indicates that autistic women in the Netherlands experience distinct barriers to adequate healthcare, including attitudinal, communication, information, environmental and systemic barriers. This report suggests research-based steps that can be taken to remove barriers to healthcare, an act that can be expected to improve both healthcare access and the health status of autistic women.

Finally, while our research participants had a variety of personal backgrounds and communication styles, we found that when given time, space and a facilitating environment, they were all capable of articulating their experiences, needs and ideas about improving care. Given the large and troubling healthcare disparities that have been documented by this and other research, this suggests that autistic women are well placed to assist clinicians and healthcare providers as they implement and assess both interpersonal and systemic improvements.

## Dissemination

In 2019, our findings were shared through conference presentations at the Female Autism Network of the Netherlands (FANN) annual meeting, the Nordic Network on Disability Research (NNDR) conference in Copenhagen, and the International Association for the Scientific Study of Developmental Disability (IASSIDD) conference in Glasgow; and also in poster form at the Iedere Patiënt is Anders congress sponsored by WOMEN INC. and ZonMW in Amsterdam and the Autisme Europe conference in Nice.

Our team is currently preparing community, public and academic outputs. A “roadmap” showing areas where sex- or gender-related issues commonly arise in healthcare for women with autism is being designed by Taluut Ontwerp (Utrecht), which is also designing a Best Practices Guide in the form of a pamphlet for clinicians. The “roadmap” can be used by patients, supporters and clinicians as a visual to support communication about solving healthcare access and delivery problems.

In addition, we will make an accessible Dutch summary of this report available. This will be distributed online through social media and autism organisations, as will the “roadmap” and Best Practices Guide. A version of the full report in English will be made available through the VU Research Portal (PURE), an open-access repository at Vrije Universiteit Amsterdam.

Two academic journal articles based on our findings are in preparation, and will be submitted in 2020.

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## Appendix A: Qualitative research participants—Demographic details

<b>Age</b>	<b>Age at diagnosis</b>	<b>Parent?</b>	<b>Working?</b>	<b>Burnout?</b>	<b>Loss of work/education due to burnout or health?</b>
<b>Interview participants (n = 14)</b>					
33	33	yes	--	--	--
42	41	yes	no	yes	yes
70	55	--	no (retired)	--	--
41	38	yes	no	yes	yes
47	41	--	no	yes	yes
28	25	no	no	yes	yes
29	29	no	no	no	yes
38	38	yes	no (student)	--	yes
45	39	yes	--	yes	yes
29	29	--	--	--	--
32	29	--	--	--	--
39	5	--	--	--	--
34	5	no	--	--	--
46	45	no	no	yes	yes
<b>Focus group participants (n = 25)</b>					
42	40	yes	--	--	--
23	5	no	no	--	--
46	44	--	--	--	--
44	44	yes	no	yes	yes
27	18	no	no	--	--
45	40	--	yes (part-time)	yes	yes
46	43	no	no	yes	yes
55	35	--	--	--	--
29	23	yes	yes	--	--
41	40	--	yes (part-time)	yes	yes
43	41	yes	no	yes	yes
21	19	no	no (student)	no	no
34	33	yes	yes	yes	yes
47	44	--	yes	--	--
32	23	--	yes (part-time)	--	--
29	27	no	no (student)	yes	yes
51	38	yes	no	yes	yes
43	36	--	yes (sheltered workshop)	yes	yes
52	52	--	no	yes	yes
56	55	yes	no	yes	yes
26	15	no	no (student)	no	no
45	35	yes	no	yes	yes
41	35	yes	yes	no	no
40	35	--	no	--	--
57	57	yes	no	yes	yes

**Note:** Participants had the option not to provide information on any topic, so information about parenting status, work, and burn-out experiences is not available for all participants.

